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Barriers to pain assessment and management in cancer survivorship

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Abstract

Introduction—Healthcare providers frequently lack the knowledge and skills to provide optimal pain management for cancer survivors. Scientific evidence and clinical guidelines are lacking in the management of chronic, persistent pain in survivors. The purpose of this article is to describe pain-related issues of cancer survivors using case presentations of selected patients enrolled in a randomized trial to eliminate barriers to pain management.

Materials and methods—Case presentations were selected from a National Cancer Institute-funded study that utilizes patient and professional educational content derived from the clinical guidelines of the National Comprehensive Cancer Network. Case presentation criteria included a pain rating of ≥ 6 and diagnosis of Stage I, II, or III of the following cancers: breast, colon, lung, or prostate cancer. Cases are presented based on the study's framework of patient, professional, and system-related barriers to optimal pain relief.

Results—Across all three case presentations, barriers such as fear of side effects from pain medications, fear of addiction, lack of professional knowledge of the basic principles of pain management, and lack of timely access to pain medications due to reimbursement issues are prevalent in cancer survivorship.

Conclusions—Chronic pain syndromes related to cancer treatments are common in cancer survivors. Patient, professional, and system-related barriers that are seen during active treatment continue to hinder optimal pain relief during survivorship.

Implications for cancer survivors—Healthcare providers must acknowledge the impact of chronic, persistent pain on the quality of cancer survivorship. Clinical as well as scientific efforts to increase knowledge in chronic pain management will improve the symptom management of cancer survivors.

Keywords

Survivorship; Chronic Pain Management; Barriers

Introduction

Cancer is rapidly becoming a chronic illness, and an estimated 10 million individuals in the United States are surviving their cancer diagnosis [1]. Although this number is expected to increase over the next decade due to further improvements in treatment and surveillance, the follow-up care of long-term cancer survivors (defined as one or more years since primary treatment) beyond active treatment has remained substandard. The health care needs of cancer survivors are unique, and many are at risk for developing late or long-term side effects from their primary treatments. These long-term effects may also hinder optimal physical, psychological, and cognitive functioning for survivors. In almost every situation these side effects are inadequately managed due to a lack of patient and professional knowledge of optimum management.

A cancer symptom-related area that has been ignored both clinically and scientifically is chronic pain. Pain is recognized as impacting all dimensions of quality of life [2–5], and is one of the most distressing symptoms for cancer patients [6]. Despite this negative impact, chronic pain in cancer survivors remains poorly studied with limited clinical advancement. The incidence of pain during the early course of disease is estimated to be around 50%, and this number increases to approximately 75% in advanced disease [5]. Furthermore, the growing number of cancer survivors translates to a growing population of survivors who are elderly [7]. This phenomenon means that elderly survivors are at greater risk of not only experiencing late effects from treatment, but also surviving with co-morbidities that cause pain [7].

The literature has identified a number of common health-related concerns in long-term survivors that may contribute to chronic pain. The prevalence of arthritis and osteoporosis were reported to be the most common co-morbidities in a sample of long-term cancer survivors, and the severity of these conditions increased over time [8]. Long-term cancer survivors were also found to have significantly higher levels of physical symptoms when compared to healthy individuals [9]. In a study with short-term breast cancer survivors (1 month after surgery), Katz and colleagues found that correlates of acute and persistent pain included age, marital status, and being treated with more invasive surgeries [10]. Previous systemic therapies (either chemotherapy or hormonal therapy) were also found to predict chronic pain in long-term survivors [11].

Some data exist on posttreatment pain syndromes that are secondary to chemotherapy, radiation, and surgery. Chemotherapy-related chronic pain syndromes include painful peripheral neuropathy, as well as osteonecrosis or avascular necrosis from chronic corticosteroid use as pre-medications in chemotherapeutic regimens [12–14]. The development of persistent peripheral neuropathy is largely dependent on factors such as age, co-morbidities (i.e., diabetes), cumulative dose of chemotherapy, and impaired drug metabolism [15,16]. Avascular necrosis secondary to corticosteroid use often occurs in the femoral or humeral head which leads to decreased range of motion, pain with movement, and arthritis [5]. Radiation-related pain syndromes are caused by neural damage or tissue fibrosis and may occur up to 20 years posttreatment [17,18]. Radiation-induced brachial plexopathy is found in breast cancer survivors, with approximately 9% of breast cancer survivors experiencing at least mild plexopathy [13,19]. Chronic pelvic pain secondary to radiation has been reported in prostate cancer survivors, and is usually described as brachytherapy-related dysuria, with 20% of patients reporting the symptom 1 year posttreatment [20,21].

Finally, surgery-related chronic pain syndromes are common in breast and lung cancer survivors. Chronic pain is seen in 50% of mastectomy patients [22]. Pain in women who underwent breast-conserving surgery with axillary node dissection is reported to be around 39% [12,23,24], with moderate to severe pain reported by 10% of women 1 year

postoperatively [25]. The incidence of chronic post-thoracotomy pain (CPTP), defined as an aching or burning sensation that persists or recurs along the thoracotomy scar postoperatively, is estimated to be around 26–67% in the current literature [26–29]. Dajczman and colleagues followed patients post-thoracotomy for up to 5 years and found that pain persisted in 50% of patients at 1 year, 73% at 2 years, 54% at 3 years, 50% at 4 years, and 30% at 5 years [28]. The majority of patients do not seek pain management, even though approximately 50% of patients report functional limitations by CPTP at 1 year post-thoracotomy [30,31].

There is an emerging body of literature that addresses symptoms in elderly cancer survivors [32,33]. Given and colleagues identified predictors of pain 1 year following diagnosis in elderly cancer patients, and these included stage, more comorbidities, and the diagnosis of lung cancer [34]. Symptom severity, such as pain, are significant predictors of physical functioning and depressive symptomatology [35–38]. Taken together, the emerging literature suggests that elderly cancer patients suffer from pain related to previous treatments and co-morbidities, and aggressive management of chronic pain is critical for the long-term functional and psychological well-being of this vulnerable population.

One framework often applied to understanding the reasons for unrelieved symptoms is to examine the barriers to their relief. These barriers are often classified into three categories: patient, professional and system barriers [39]. Patient-related barriers to pain assessment and management include reluctance to report pain, fear of side effects, fatalism about the possibility of achieving pain control, fear of distracting physicians from treating cancer, and belief that pain is indicative of progressive disease [3,40–46]. Professional barriers include lack of knowledge of the principles of pain relief, side effect management, or understanding of key concepts such as addiction, tolerance, dosing, and treatment of neuropathic pain [47–54]. System-related barriers include low referrals to supportive care services, as well as external system barriers including reimbursement and regulatory constraints [55–57]. While these categories represent common pain barriers in cancer survivorship as well, other barriers may exist that are unique to survivors.

Polomano and Farrar categorized factors contributing to underreporting and undertreatment of pain in cancer survivors as science-related, practice-related, and patient-related [58]. Limited research addressing pain in cancer survivorship contributes to the undertreatment of chronic pain. Practice-related factors include knowledge deficits, failure to acknowledge chronic pain after curative therapies, failure to inform patients of long-term pain-related consequences, and misconceptions regarding recovery from treatment-induced pain [58]. Finally, patient-related factors include reluctance to report pain, worries about long term use of pain medications, and denial of pain due to fear of disease recurrence or progression [58,59]. Table 1 provides a list of common barriers to optimal pain relief in cancer survivorship.

The purpose of this paper is to describe barriers to optimal pain relief in cancer survivors through case presentations of select patients enrolled in a National Cancer Institute-funded study to test the effects of an intervention on eliminating these common barriers.

Materials and methods

Study design and selection of cases

The primary aim of the “Barriers to Pain and Fatigue Management” study is to test whether an educational intervention eliminated barriers to symptom management and decreased symptom severity. Education content was derived from the evidence-based guidelines for pain as developed by the National Comprehensive Cancer Network [60,61]. The criteria for selection of cases presented in the study was pain >4 although cases selected for inclusion in this paper have pain >6 to illustrate those with the most severe pain. Patients had a diagnosis of Stage I,

II, or III disease. The criteria were intended to select patients with moderate to severe symptom intensity who would provide a perspective of the issues faced by cancer survivors with chronic, persistent pain. Cases were selected from patients enrolled in the intervention phase of this experimental trial. Three cases were selected from a total list of 50 study patients, and cases were reviewed by the research team in order to select those felt to best illustrate pain management in cancer survivors. Survivors selected were limited to those patients who were within 1 year of completing primary treatment.

Case #1: patient-related barriers

Patient J was a 70-year-old female with Stage IIIa lung cancer. The patient had completed three cycles of induction chemotherapy, followed by right upper lobectomy and mediastinal node dissection. Adjuvant concurrent chemoradiation was completed postoperatively. All treatments were completed 1 year ago. Co-morbidities included COPD and arthritis. The patient rated her pain as 7/10, and her pain was primarily located in the back and hip secondary to chronic arthritis, residual peripheral neuropathy from chemotherapy as well as surgery. Her neuropathic pain was confined to her feet, and post-surgical pain was located primarily in the right chest area. Pain medications were prescribed, and included opioids, ibuprofen, and gabapentin. The patient was unwilling to take her pain medications on a consistent basis. This reluctance was based on her personal experiences while taking care of her husband who died of cancer 1 year ago. The patient stated that she would rather be in pain than “feel goofy” while on opioids. She was only willing to take ibuprofen on an as needed basis, despite encouragement from the healthcare team to take the ibuprofen on a scheduled basis. The patient reports dramatic decreases in her already-compromised functional status since completing primary treatment.

Discussion

Reluctance or refusal to take pain-related medications as prescribed is a common and recurrent barrier to optimal pain relief. In many situations this reluctance or refusal is based on personal experiences as a caregiver or through observations of suboptimal pain management [62]. Concerns regarding side effects of pain medications may also hinder optimal pain relief [58, 59]. Common side effects from opioid-containing pain medications include somnolence, nausea, and constipation. Some of these side effects, including somnolence and nausea, may hinder optimal functioning for cancer survivors. Returning to and maintaining normalcy after primary cancer treatment is important to survivors, and this often entails returning to employment. The somnolence, lethargy, and nausea that often accompany pain medications are important factors that survivors might not be willing to tolerate. Similarly, mismanaged side effects lead to unnecessary suffering and hinder patient’s willingness to continue treatment.

With long-term survival of cancer, and painful effects of treatment such as peripheral neuropathy experienced by this patient, the treatment of pain as a survivorship concern will be paramount. The treatment-related chronic pain syndromes (peripheral neuropathy and chronic post-thoracotomy pain), coupled with co-morbidities (chronic arthritis), severely compromised the functional status of this cancer survivor.

Case #2: professional-related barriers

Patient L was a 61-year-old male with Stage II prostate cancer diagnosed 2 years ago. The patient was treated with radical prostatectomy and was receiving continued combined androgen deprivation therapy with hormonal agents. Co-morbidities included arthritis and asthma. The patient rated his pain as 6/10, and pain was primarily due to osteoporosis resulting from long-term hormonal therapy. The patient was on opioids as needed for pain management and was also taking calcium/vitamin D supplements for the osteoporosis. The patient experienced an

exacerbation of his pain secondary to a recent neck surgery and sought care from his surgeon in the community. He was placed on MS Contin and gabapentin 600 mg twice a day after insisting on stronger medications. His pain rating has since increased to 8/10, and he continued to experience pain secondary to osteoporosis and side effects from hormonal therapy.

Discussion

The case above illustrates a poor standard of care related to ongoing management of this patient's pain. The treatment trajectory for this patient is unclear; this is common for prostate cancer patients who completed surgical treatments and are placed on long-term hormonal therapy. One of the common side effects from long-term hormonal therapy is osteoporosis, and with the uncertainty in duration of treatment this patient will continue to suffer from osteoporosis-related pain. The patient's increasing and complex pain was also not managed in an aggressive way that would enhance quality of life during survivorship. Healthcare professionals often create barriers to cancer pain management. One of the most serious professional barriers is the severe deficits in skills and knowledge related to pain assessment and management. This problem stems primarily from a lack of fundamental training in healthcare professional's curriculum while or in continuing education [51]. Nurses and physicians often express misconceptions of pain management, particularly regarding the use of morphine and other opioids. These common misconceptions are similar to those found with patients, and include drug tolerance, the belief that pain is inevitable in cancer, addiction, and misunderstanding of morphine-related side effects [43,54]. Studies assessing physician knowledge and attitudes in cancer pain management have documented that knowledge deficits exist across practice and specialties [43,58,63]. Oncologists are found to be most knowledgeable of guidelines to manage cancer pain when compared to family practitioners and other providers [63]. This factor is particularly important in cancer survivorship since the majority of survivor care is expected to be performed in the community setting [58]. Therefore, the quality and quantity of education of healthcare providers, regardless of practice and specialty, must be addressed to improve pain management for cancer survivors.

Case #3: system-related barriers

Patient P was a 53-year-old African American female with Stage I breast cancer. The patient's primary treatment included skin-sparing total mastectomy with sentinel node biopsy as well as adjuvant chemotherapy, with breast reconstruction completed after adjuvant treatment. Co-morbidities included diabetes, with a history of diabetic neuropathy, and arthritis. The patient's pain rating was 7/10, and this pain was primarily described as neuropathy of the hands and feet that was interfering with activities of daily living. The patient's diabetic neuropathy was exacerbated by the paclitaxel that the patient received as part of her adjuvant chemotherapy. Pain medications included pregabalin for peripheral neuropathy. Based on tumor receptor status, the patient had also received 3 years of hormonal therapy with an aromatase inhibitor. This treatment was discontinued early due to severe myalgia and arthralgia. The hormonal therapy had also exacerbated the chronic arthritis that the patient was already suffering from. The patient was on a COX-2 inhibitor for her arthritis. Upon further questioning the patient reported that she had problems procuring the prescribed pain medications due to insurance problems. After beginning treatment, the patient rated her pain as 5/10, with some improvement with neuropathic and arthritic pain. However, she continues to suffer from moderate pain with intermittent balance and gait disturbances.

Discussion

This case is a prime example of the influence of co-morbidities on treatment-related pain. Chronic peripheral neuropathy is common among breast cancer survivors, and patients who also suffer from co-morbid conditions such as diabetic neuropathy often experience an

exacerbation of their neuropathic pain. The joint and muscle pain commonly seen in breast cancer survivors receiving long-term hormonal therapy increase the severity of chronic pain. System-related barriers such as reimbursement policies, health policies, as well as social implications can also impact tremendously on pain relief. It is not uncommon to find that patients encounter systematic barriers when attempting to fill an opioid prescription [55]. These systematic barriers to filling a prescription include inability to afford medications, restrictive reimbursement policies for managed care, as well as failure of community pharmacies to stock opioid medications [43,49,55,56]. Opioids and other controlled substances are under intense scrutiny by federal and state regulators [57]. The diversion of opioids has led to fears of robbery in community pharmacies [49,64]. Fear and concerns related to federal or state investigations are of even more concern for clinicians and pharmacies [43,49,57]. As the case above illustrates, eliminating barriers to pain management means addressing system barriers.

Conclusions

The number of cancer survivors will increase significantly over the next decades. The quality of survivorship for cancer patients must extend beyond the survival of disease and include symptom-related concerns such as chronic, persistent pain. The common patient, professional, and system barriers to optimal pain relief documented in cancer as well as non-cancer patients are present in cancer survivors as well. To eliminate these barriers, strategies must address each category simultaneously rather than sequentially. The relationship between barriers within each category are intertwined, and failure to address one area will hinder success in another.

Patient-related fears, including the potential long-term use of pain medications in survivorship, must be addressed with adequate education and follow-up care. Professionals must acknowledge that pain is a chronic concern in cancer survivors, and clear clinical guidelines and resources must be developed to address the proper assessment and management of chronic, persistent pain (see Table 2). Pain management should be included in survivorship care plans and patient education. Education of federal and state policy boards should be undertaken to aid in eliminating system barriers to optimal pain relief. Furthermore, the effects of co-morbidities on chronic, persistent pain in cancer survivors needs to be explored further. Emerging data from the current literature suggest that co-morbidities in long-term cancer survivors may predict physical functioning and symptom burden [7,34]. The incidence of some of the most common survivable cancers (i.e. breast, prostate) are higher in older adults [7]. This group of cancer survivors are particularly vulnerable to the effects of chronic pain due to high incidence of multiple co-morbidities related to aging. Co-morbidities have been reported to affect about 70% of cancer patients [7]. Finally, research into the pain assessment and management needs, as well as the implications of chronic, persistent pain must be conducted in order to advance the clinical and scientific knowledge of this neglected issue in cancer survivorship.

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Table 1
Factors affecting optimal pain relief in cancer survivorship [7,58]

Factors
Patient-factors
Co-morbidities
Aging
Reluctance to report symptoms
Fear of recurrence
Symptoms as a reminder of cancer
Perceptions of pain
Negative experiences with pain medications in the past
Lost to follow-up after primary treatment
Professional-factors
Lack of knowledge in
Prevalence and incidence of chronic pain
Assessment and management of chronic pain syndromes
Basic pain assessment and management skills
Not informing survivors of potential of developing chronic pain
Lack of comprehensive and clear guidelines for follow-up care of survivors
Scientific factors
Limited research in chronic pain syndromes
Lack of well-validated research instruments in chronic pain
Limited research in the quality of cancer survivorship

Table 2
Selected resources and references in chronic pain

Resource/reference	
1	The National Comprehensive Cancer Network. <i>Practice Guidelines in Oncology: Adult Cancer Pain version 1.2007</i> . Retrieved from http://nccn.org .
2	American Pain Society. <i>Guideline for the Management of Cancer Pain in Adults and Children</i> . Retrieved from www.ampainsoc.org
3	National Institutes of Health State-of-the-Science Statement: (2002) <i>Symptom management in cancer: Pain, depression and fatigue</i> . Retrieved from http://consensus.nih.gov/2002/2002CancerPainDepressionFatigues022main.htm .
4	City of Hope Pain Resource Center. http://www.cityofhope.org/prc/
5	Survivorship Education for Quality Cancer Care. http://www.cityofhope.org/CME/Survivorship/SurvivorshipHome.htm